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ABSTRACT

This booklet, developed by parents of children with developmental disabilities, is intended to help policy makers understand major parental concerns about raising a child with a disability. The specific issues addressed are: (1) the special needs of families with a disabled child; (2) the right to community integration; (3) the continuing difficulties in obtaining appropriate care; (4) the continuing difficulty of obtaining an appropriate public education in the least restricted educational environment, as required by law; (5) the need for better integration of available services; (6) the continuing obstacles despite accessibility requirements under the law; (7) special medical care problems; (8) the continuing problems with employers despite relief offered by the Family and Medical Leave Act of 1993; (9) finances, a constant source of stress to these families; (10) the continuing lack of accessible transportation services; and (11) the future, the dream of a future where every child is happy, loved, and successful. Each section contains factual information about the issue, an analysis of how families are typically affected, and quotations by family members describing their specific experiences. The booklet concludes with suggestions for both policymakers and parents. (DB)

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Maine's University Affiliated Program
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The contents of this book do not necessarily represent the policy or position of the U.S. Department of Health and Human Services or the University of Maine.

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Your decisions on these issues affect our families.

Before you decide,

we want you to know

how your decisions

will affect families.

Every child is born into a family. In turn, the family is part of a greater community. For all families, the presence of a child brings added responsibilities and demands. Although these obligations can be stressful, the child still brings great joy to the family as parents watch the child develop. As the child grows older, his or her time in the community increases while time with the family decreases. Eventually, it is assumed that the child will become a contributing adult member of the community.

For families who have children with disabilities, this process is often skewed. The presence of a disability intensifies all interactions surrounding the child, whether within the family unit or in the community. Families may be confounded by medical concerns, the lack of appropriate child care or transportation, and the inability to find needed therapeutic services. They agonize over how they will pay for these services while balancing the needs of their other children, their spouses, and their jobs. Families may struggle to meet the unique needs of their children with disabilities often at great physical, emotional, or financial expense. Families want to raise their children at home, but they may not be able to do so without support. Some parents fear that they will have to relinquish control or even custody so that their child may receive the supports and services he or she needs. If custody is given up to the state, and the child is placed outside of the home, the expense to the state/community becomes five to eight times greater than when the child remains at home.

Many families who have children with disabilities are not or do not feel part of their community. A lack of awareness and a reluctance to become involved have contributed to the exclusion of people with disabilities from community places and events that are commonly frequented by people without disabilities.

There are laws (e.g., Americans with Disabilities Act, Individuals with Disabilities Education Act, Section 504 of the Rehabilitation Act of 1973) and agencies that have been designed to help families who have children with disabilities. The principles and ideals behind these are fundamentally sound. Families, however, often feel that the laws and services do not always have the desired impact on the individuals for whom they were intended. Rather than providing support, agencies can become a source of frustration to families who struggle to make sense of complicated forms, lack of interagency collaboration, varying eligibility requirements, and inadequate information.

Parents of children with disabilities are not seeking special treatment for their children. They want only what other parents and children take for granted: the chance to be an integral part of their communities. For this to happen, they need to be assured of equal access to all public environments that are afforded them through federal and state legislation. They need support to achieve what we all want — to live, to learn, and to love.

Policy makers cannot take away the challenges that families experience, but there are things that they can do that will make a positive difference in their quality of life. Each piece of legislation and policy must be evaluated on an individual basis as the needs of each person, with or without disabilities, must be assessed on an individual basis. An important question for legislators to ask when making a decision is, "Will this assist people with disabilities to achieve happy, healthy, and satisfying futures?" The way you, our policy makers, respond to this question will affect individuals with disabilities and their families.

To help you understand what families need, a group of family members decided to share their experiences. This diverse group of parents met as part of a training on positive supports sponsored by the Center for Community Inclusion, Maine's University Affiliated Program. The training was funded by the U.S. Department of Health and Human Services, Administration on Developmental Disabilities. In addition to learning about positive supports to address the challenging behaviors of their children, parents were offered the opportunity to work on a group project. They decided to tell their stories to policy makers. These parents want to help people who may not have experience with disability issues to understand what their lives are like. Even though you do not know them or their children, every decision you make regarding work, child care, health care, communities, services, finances, and transportation can have an impact on their lives. Whether the impact is positive or negative will be up to you. A decision can be made in an instant, but families must live daily with the consequences of your choice.

The following collection identifies issues that are important to families. The center column contains factual information about each issue followed by an analysis of how families are typically affected. The family members' quotes on the borders describe some of their experiences. Each family's experience is different. Each story becomes a unique part of a mosaic that we hope will provide you with some insight into the joys and struggles that families who have children with disabilities face daily.

—Marsha J. Clark, Ph.D. and Martie Kendrick

Family

All of us have different life styles, yet we all have a difficult time maintaining a balance in our lives. There are so many extras going on in our lives, such a high price we pay for trying to do it all.

Stacie

I am the constant, the one who deals with the meetings, the evaluations, and the professionals. Gramma gets to do the fun stuff. Thank God for Grammas.

Tonya

My sister has had numerous people in and out of her home, making her feel like she lives in Grand Central Station. This is extremely difficult because her privacy is gone. She does it because she needs them and so does her son.

Linda

I have heard from parents who have made the decision to have their children live outside of the family unit. I know that they have done everything they could before they made that decision. It is something they discussed at length. The reality is that families who do not have children with disabilities do not have a conversation about whether they could, should, or are supposed to be intact. It's assumed.

Sue

It is not easy to make a two year old and a four year old understand that I am not only their mother, but that I am also the legal advocate for their brother.

Tonya

Families who have children with disabilities are like other families. They have the same hopes and dreams for their children. They want their children with disabilities to remain an integral part of their families. Their needs, however, are intensified by the presence of a child with a disability. While other families are busy in the pursuits of daily living and fun, families of children with disabilities must deal additionally with a variety of doctors, therapists, insurance personnel, school staff, social agencies, Medicaid, and more. Besides being simply a "mom" or a "dad," parents must be teachers, therapists, and case managers. The number of telephone calls parents must make to assure service coordination can be daunting. Often, extended families are unable or unwilling to assist the family in times of need, simply because of the child's disability. Sometimes a relative's judgmental attitude may add to the stress of an already overwhelmed parent. Often parents wonder where they will find the time, energy, and strength to continue.

I worry about his violent rages. He is only eight years old and it is becoming more difficult to set limits and manage him physically. I worry that he will become too violent and will be unable to remain living at home with us.

Janice

There are some members of my family who won't take care of Amanda. Why? Because they are scared of what they don't know and aren't willing to take the time to find out. They are missing so much by not being close to Amanda.

Dawn

We are normal, average parents in tough situations. This is how we have coped or haven't coped. It drives me crazy to hear, "You're such a special person!" What choice do I have? Should I send him to an institution or keep him at home? No manner. I'm keeping him home!

Janice

My sister took both of my children for a day. When she returned, she said, "You deserve a medal, how do you do it?" She didn't mean it negatively, but it didn't help me.

Janice

When Matt came out of the hospital, I was crying with a friend. She said, "You don't have to keep him at home." I told her, "You don't understand, I do. We are a family."

Sue

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Community

Our family just wants to be treated equally, not with pity.

Stacie

Because your child has a disability you are made to feel that you are not smart enough, you don't provide enough, you don't listen to the "right people," you're over protective, or you're making them sicker. You don't get these feelings from people about your other children.

Dawn

It is so hard to explain to people about Scott's problems. Outwardly, he is a tall, handsome boy. Inside he has a terrible neuro-biological disorder that has devastating effects on our family.

Janice

Every time I hear about someone with a mental illness committing a crime, my heart skips a beat. I wonder what kind of services were not in place to prevent such a tragedy.

Sue

I fight constantly to keep Brandon included in kindergarten. Some days it feels like a losing battle. I get exhausted trying to be his mother, advocate for his needs, and teach the professionals how to communicate better with him.

Tonya

Scott would like to have some friends, but his social skills are so awkward. He often alienates other children with his inappropriate behaviors.

Janice

In the past, society has excluded and segregated people with disabilities. Children and adults with disabilities were believed to be better served in institutional settings away from their families and communities. As a result, communities began to believe that people with disabilities were intrinsically different from the rest of us. They are not. All children benefit from being raised in a loving family and from being part of a supportive community. Current laws (e.g., Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973) support the rights of individuals with disabilities to be an integral part of their communities. Unfortunately, attitudes have not kept pace with the law. Parents often feel ostracized when their children with disabilities are in the community. Many parents are told that their children with disabilities cannot participate in programs that are available to their other children. Families spend much time and energy trying to ensure community access and acceptance.

I would like my daughter to belong to a society that empowers her to full citizenship, expression of her talents, and commitment of her gifts.

Roberta

An interesting transformation happens to me when I enter a room in my community for a meeting. As I enter the room I am a middle income, intelligent, professional member of the community. When I share that I am a parent of a child with special needs, my credibility decreases immediately. I become associated with all of the stereotypes about parents of children with disabilities – low income, doesn't work, a taker, a complainer, someone who doesn't care about her child, and above all someone who must have done something during the pregnancy to cause the disability. As hard as I try, I can never completely regain the level of status and respect I had when I entered that room.

Dawn

When you have a child with a disability, something as simple as sitting down to dinner, grocery shopping, or a doctor's appointment isn't simple anymore.

Stacie

There are always things that the parent just can't take care of alone. We need the assistance of the community, the local educational system, and support services. We are doing all we possibly can and sometimes we just need help.

Sue

Child Care

Respite services are a lifesaver, but it is so hard to keep good caregivers. It is a tough job and the providers don't get paid for four to six weeks.

Dawn

Our family needs more respite care and services for us to maintain Scott in our home. I have to be strong, and it is so stressful living with Scott. I am worn down and drained by the daily stress. It feels like our home is a psychiatric unit.

Janice

Chris has been receiving home health services since he was four. His family has been working on his self-help skills. It is so difficult for Christopher to learn new skills when there is little consistency in his life. Home health is so volatile. You can barely count on coverage and staffing. His family never knows whether Chris will have staff from one day to the next.

Linda

I have respite, but I'm afraid to use it because I'm not just going to leave my son with anybody. I need to trust the person who will be providing respite and know that my son will be safe.

Tonya

The last three times I've scheduled respite, the providers were unable to be there or cancelled at the last minute.

Candice

I hope to some day see a therapeutic day care for school-age children, not just for preschoolers.

Tonya

The Americans with Disabilities Act (ADA) recognizes child care facilities as public accommodations and therefore, addresses their responsibility to provide services fairly and equitably. ADA states that child care providers must make "reasonable accommodations."

Despite this support from ADA, many families of children with disabilities continue to be denied access to child care facilities. Programs frequently decide that they are not qualified to care for children with disabilities. Parents whose children also have challenging behaviors have a more difficult time finding child care. Although a child may initially be allowed to enter a program, as soon as difficult behaviors emerge, the parent is told to remove the child. Respite programs should function as a temporary relief for families, but typically respite has a limited availability of trained caregivers as well as long waiting lists. This means that many parents have no break from their children to do simple tasks such as grocery shopping nor the opportunity for an evening out.

My son has been without child care for over four months because he requires a one-on-one aide in the child care setting for safety reasons. I have spoken with a congressman and members of the Children's Task Force. I still have no answers and my son still has no child care.

Tonya

If respite care people got paid what they should get paid, think of the wonderful people you could hire. Good people could quit a lower-paying job to do something they love to do.

Esther

I manage to work 20 hours a week outside the home and get out once a week with friends. It takes one child care center, two teenage baby-sitters, one respite provider, a few great friends, and a grandmother to take care of my three children during these times.

Sue

I was called at work by Brandon's child care provider on his first day, after he had been there for only two hours. This center has the reputation for being one of the best in the area. I was told to come pick him up and my money would be refunded.

Tonya

Bryce was expelled from the after school program for leaving the playground. He was looking for me because I was meeting with his teacher that day. There was no suggestion of working together to find ways to accommodate his needs.

Candice

Education

The school philosophy, that all students are individuals and we should treat their needs individually, is a facade. When it comes to my child, their philosophy isn't individualized! They're saying it, but it isn't happening.

Stacie

Most teachers want to do what is best for all of their students. Most became teachers because they enjoy working with children. Teachers do the best they can, but the educational system lets them down, and in turn, children, parents, and communities. They aren't given enough training, time, money, or supports. When this happens, it always comes down to money. Why? Aren't children worth it?

Nancy

Life is not just complicated at home. It is also a challenge at school getting the educators to understand and accept our child for who he is, not what he can or cannot do.

Stacie

The one major positive factor in Christopher's life is the school system. Chris has an aide, Gary, who has been with him for three years. Gary has helped to teach Chris consistency, social skills, and academics. Gary has even done respite care when the home health agency was unable to. Talk about dedication.

Linda

Why do we have to push to get the laws enforced? Why can't they just follow them?

Diana

Free appropriate public education in the least restrictive educational alternative is afforded all children under federal (Individuals with Disabilities Education Act, P.L. 94-142 as amended, 20 USC 1401 et seq.) and state law. This means that children with disabilities have the right to receive the supports and services necessary for their education in their neighborhood schools with their siblings and peers. Most parents of children with disabilities want their children educated alongside their non-disabled peers provided that the necessary supports are in place. Many children with disabilities are not given this opportunity. For those who are, many do not receive the needed supports to make this educational opportunity successful. As a result, parents face seemingly endless meetings, children with disabilities may receive less than adequate educational programming, and teachers often feel imposed upon and unqualified. When parents offer suggestions, they are often ignored because they are "just parents." Typically, when parents have difficulty with the schools it is because they feel that people do not abide by the spirit of the law.

We had 13 people at a meeting last week. Most of the accommodations my son needed take time, energy, and commitment. No new people. No new dollars. He doesn't need gold stars, just someone to say, "It's nice to see you." Sometimes a child's success isn't about dollars and cents, it's about the commitment of people.

Sue

The meeting that took place before Brandon entered elementary school had a total of 17 people present. This was just to decide whether he should be included in a kindergarten class and what services he needed.

Tonya

As a teacher and coach, I fear that Brett will be the one child no teacher will want in his class and no coach will want on her team. I hope it doesn't happen.

Nancy

Annie's teachers have been great. They have been sensitive not only to her physical and academic needs, but also her social and emotional challenges. They have been supportive and let her gain independence at the same time.

Roberta

Parents count on teachers to help figure out why their child is having difficulty at school. After all, they are the professionals. Yet when a teacher stands up and says, "The parents and I can't figure out the troubles this child is having. We need to find out why," the teacher often becomes at odds with administrators.

Nancy

Services

When I try to call a state agency I hang up the phone and say, "Oh, I hate calling a state agency!" It doesn't matter which one.

Dawn

I have to struggle to get the services my child needs. If he were in foster care these same services would be mandated.

Sue

You only hear about the abuses of the service delivery system. You don't hear about those who really need it, are getting it, and are using it effectively.

Diana

Rolling over, reaching for toys, sitting, speaking, and crawling were accomplished with the help of skilled therapists, special equipment, and lots of family time. Her first words came in a therapy session, "I did it!" Her first steps? Also in a therapy session at the age of three and a half.

Roberta

Chris has been involved with the Department of Human Services since he was 18 months old. My sister did not find out about the Katie Beckett Medicaid Waiver Program until he was five. Every social worker she spoke with always asked, "What is it that you need?" They didn't tell her what was available for services for her child so she could at least choose what she deemed appropriate.

Linda

I get exasperated when I am given a brief period of time to get paper work together and the state agencies seem to have no concern or concept of time for themselves.

Tonya

There are many state and federal agencies designed to provide support to children with disabilities and their families. The array of services and service providers attempting to meet the needs of children and adults with disabilities can be overwhelming. Knowing where to start is difficult for many families. When people do begin working with agencies, they often find it frustrating, confusing, or ineffectual. Parents typically experience service delivery systems as cold and punitive rather than providing the needed assistance and support. Complex rules, forms, and procedures that are put in place to regulate the system often become obstacles to families and individuals with disabilities who are trying to get the basic services they need. Additionally, agencies typically work in isolation, with no coordination between agencies. Parents must then become case managers for their children to ensure that all of the needed services are obtained and coordinated. The systems that were put in place to help families often become major stressors instead of supports for them.

Today we buried Michael, the son of my mother's friend, who was found dead in the river at 32 years old. Michael had schizophrenia, and there had been no services or programs to help Michael since he left high school. His family tried to love and care for him, but unmedicated and unsupported, he was left blowing in the wind. His violent outbursts made it impossible for him to live with them. I cry for Michael's mother and I cry for the future of my own 8 year old boy with mental illness. I light a candle for some hope. I hope that all the letters, committee work, and calls for services will keep this kind of nightmare from happening to our family.

Sue

Bits and pieces, that's how we learn about the resources and supports. Sometimes we get information after the fact. Then it's too late, and we lose out. Agencies often don't know who or what is available to assist us, so we stumble around in the dark.

Nancy

When Amanda was an infant we found services through a friend of a friend. Child Development Services (CDS) was the fourth or fifth group we contacted. While it was known one week after Amanda's birth that she was blind, we were not referred to CDS and we did not connect with them till she was one year old.

Dawn

I have found out that there is a lot of help out there, but it's all in who you know. It is very political.

Candice

Accessibility

I want someone to say, "That little girl is lucky to have a mom like her," because I know she wouldn't be where she is if I hadn't been pushing for her. I'll continue to push for her so she can be her best.

Diana

Well-meaning people sometimes plan parties or activities just for children with special needs. To us, however, it feels like segregation. Why do they think our children would not enjoy being with their typical peers?

Martie

I live with the fears that there will be inaccessible places, that misconceptions and prejudice will stand in Annie's way, and that I will not be able to dissolve every barrier for her.

Roberta

Amanda is in a recreational program. She enjoys the class and has made many friends. One little girl, however, made it very clear that she did not want anything to do with Amanda. She avoided Amanda. I can't help but wonder how this made Amanda feel. The difficult part for me was seeing this happen at such a young age and knowing that Amanda will have to deal with this all her life.

Dawn

When I try to get needed services for my child, I must talk in non-feeling, intellectual ways because I need people to listen. This is difficult because I have so many emotions, and I am just trying to make a life for my children and myself.

Sue

In spite of the gains made by the Americans with Disabilities Act, access continues to present obstacles for families who have children with disabilities. Most people with disabilities face barriers every day, such as negotiating a set of stairs, getting to an important meeting, joining a club, or participating in a recreational sport. For families who have children with disabilities, access means more than simply being able to physically enter a building or event. Access for them also means having their children participate in after school programs, take swimming lessons at the local pool, join the boy or girl scouts, or attend Sunday school at their church. Many parents cannot assume that their children with disabilities will have access to these options as readily as their non-disabled children. Parents are often told that staff are not trained, there is not adequate staffing, it will be disruptive to the other children, or it will take too much time. The responsibility then falls on the family to address these issues if access is to be attained.

When it was time for Nina to go to preschool, she was not potty-trained and barely had any verbal skills. It took me 13 tries to find a preschool. It was a devastating process. Most schools simply refused Nina, while others had responses such as, "How much will she take away from the other kids?" and "How important is it for us to understand what she is saying?"

Diana

Our local community center has no wheelchair ramp. Our local general store has wheelchair access only to the take-out window which is closed all winter.

Candice

I learned quickly not to share that Amanda has special needs until after potential providers have met her. Once people meet Amanda they realize that including her doesn't have to be that complicated.

Dawn

I can truly say that everyone who touches the life of an individual with a disability can make a positive or negative impact on the future of that individual. The choice is theirs to make. A little education, understanding, and compassion go a long way.

Nancy

Finding child care is a nightmare! I knew adults discriminated against other adults, but it never crossed my mind that the same cruelty and close-mindedness could be displayed by adults toward children.

Dawn

Medical Care

When Nina was two years old, she was extremely frustrated and cried often. She had no verbal skills at all. Our doctor said she was the victim of the dreaded fourth child syndrome. In other words, we were doing everything for her. He suggested holding her drink away from her until she attempted to make the "d" sound. I did this once. Nina became so angry and confused she just sat in the corner crying. I was angry at the doctor for suggesting such an inhumane thing and was even angrier with myself for following his instructions. Eventually, we found someone who put a name on what Nina had — oral and verbal dyspraxia. It's like having a stroke and knowing what you want to say, but not being able to talk.

Diana

The cost of medical care can be astronomical. We belong to an insurance program that gives us a prescription card because medications can easily cost well over $1000.00 a month. On top of this, there is the cost of doctor's appointments, illnesses, accidents, and the other "normal" medical expenses we incur.

Nancy

One night when Bryce was two, he had a fever of 106. I rushed him to the hospital and found out that he had a kidney infection. I was told that he should have been catheterized since birth. His kidneys were damaged. I was angry at myself for not knowing. I was angry at the doctors for not realizing this sooner.

Candice

It is important to most people to have a trusting relationship with their primary care physician. For parents of children with disabilities, it is critical. Finding competent pediatricians, neurologists, or psychiatrists who can work effectively with families and children with disabilities can be challenging. While parents may begin questioning if there is a problem when a child is still young, physicians often are reluctant to make a diagnosis. Physicians may take a wait-and-see attitude, minimize parent's concerns, or even imply that the parent is doing something wrong. Many physicians have never seen a child with Rett syndrome, Cornelia de Lange syndrome, Fragile X syndrome, or sensory integration dysfunction. Lack of appropriate diagnoses prevents many children from receiving essential services. To find physicians with the required expertise, parents must frequently travel great distances. This takes time, money, energy, and perseverance. Parents also need access to up-to-date medical information and research so they can make informed decisions about their child's health.

I am still amazed at how many of us were raised to believe that doctors are "gods." We believed what they said without question. I believed what a doctor said even though she had no factual basis. It has taken numerous experiences with a variety of professionals to learn that doctors, therapists, and all professionals are just people. Some are in the job only for the paycheck, and some for the right reasons. Some love children, while some do not. My job is to pull the best team of professionals together to care for my daughter.

Dawn

When Brett was being diagnosed with Attention-Deficit/ Hyperactivity Disorder (ADHD), we were told to try medication to see if it helped. The physician wasn't sure if Brett had ADHD. I wasn't comfortable with putting him on medication before we were sure of the diagnosis. Fortunately, he did send me to someone who knows about ADHD. There aren't a huge number of doctors with expertise in ADHD, let alone close to where we live.

Nancy

Our son has been so difficult to manage with medications. It is very scary for Scott. He has been suicidal and violently out of control. We see the best doctors, but there are no easy answers.

Janice

Adam's physician has shared with me that he has a nephew with autism. Naturally, he has an understanding of what our family is going through.

Stacie

Work

Being a working parent is difficult in the best of situations. I have an excellent employer. For the first two years of Amanda's life I was able to work some of the time at home, only going to the office a few days a week. People said I had it so easy. It wasn't. I was dealing with Amanda's issues, taking her to endless appointments, and then working late hours to make up missed time. More was expected of me at work because I wasn't in the office.

Dawn

I get tired of people asking me, "What do you do for work?" I "work" 24 hours a day, seven days a week so that my son may have a future. Plus, I raise his two younger siblings. I am learning to say, "I am a professional mother and an advocate for my child. I just do not get paid."

Tonya

Thank goodness for employers who are family oriented. It takes so much pressure off of me. When I feel the support given by my employer around family issues, I work harder for them.

Nancy

A man's work is seen as more important. When it is their father's weekend and he has to stay home with the children, his co-workers ask, "Why aren't the kids with their mother? Why do you have to baby-sit?" My response has been, "You are not a baby-sitter, you are their father." There is an ignorance in the workplace surrounding a father's responsibility to his children.

Tonya

The Family and Medical Leave Act of 1993 requires employers with 50 or more employees to offer workers, who have been employed for at least a year, up to 12 weeks of unpaid leave over the course of a year. Employees may use this leave for the birth or adoption of a child, to care for a seriously ill relative, or to undergo treatment for their own serious illness. This Act offers hope, but for most families of children with disabilities, its scope is too limited. For those who are employed, many work for small businesses and therefore, the Act does not apply to them. For many, the possibility of employment is not even available because there are few jobs that will grant the flexibility necessary to enable parents to meet their parenting obligations. Parents must balance work with doctors' appointments, therapy sessions, school meetings, illnesses, and lack of appropriate child care. Few employers will indefinitely tolerate an employee, even a good one, whose chronic family issues make him or her unreliable or preoccupied.

I wonder how I can get a full-time teaching job knowing that Bryce may need another surgery and be out of school for months. It's not a good way to start a new job.

Candice

I would love to work full-time at a job where I made a living wage, had adequate health care, and had the flexibility to advocate for all three of my children. Matt's pre-existing conditions make it impossible for us to get what he needs without Medicaid.

Sue

Flex-time would be wonderful if we all had it. We all have had to use our vacation time to take our children to medical appointments or for meetings with school personnel.

Dawn

My sister and I work for a great company, where the employer is really understanding. They know that she may be late coming to work because it often takes her extra time to get her son ready for school. She gets a lot of flack from the co-workers who say, "She has special privileges." Sometimes the company is okay, but the co-workers aren't understanding.

Linda

I arrive late, leave early, or don't even go to work on an average of one day a week due to appointments for my children. Some people think that means I have it easy, but I also work late two or three nights a week to "make up" the time. Not a night or weekend goes by without me doing some work at home.

Dawn

Finances

We are lucky to have very good health insurance. Annie's therapies, equipment, and medical treatment are costly. We are grateful that we can make decisions based on what she needs rather than on cost.

Roberta

My insurance company was making me pay a spend down that I couldn't afford. I had to boil and reuse Bryce's catheters because they were so expensive. The boiling would make them swell and then they were too big for him. I swallowed my pride and desperately started calling on the phone, looking for help. A social worker at the hospital finally gave me some information that saved my sanity and perhaps Bryce's kidneys.

Candice

I know our family needs to meet with a counselor to help us deal with all of the issues related to four people in the same family with ADHD who love each other. At this point, it is on hold because I don't know where the money will come from. It isn't covered by our insurance. We make do as best we can. It often is a matter of which bill is highest on the priority list this pay period. We both have college degrees in marketable areas of study. We should be able to get the counseling our family needs.

Nancy

Why is money always the first issue? Shouldn't our primary interest be what is best for the child?

Dawn

Finances are an issue for all, whether it is personal finances, the finances of a state agency, or a national budget. Everyone must determine how best to spend limited resources. Both individuals and agencies may find themselves in the difficult position of having to prioritize even basic necessities.

Financial issues are a constant source of stress for families with children with disabilities. Services, therapies, and equipment needed for a child with a disability are expenditures not typically associated with raising a child. These unexpected expenses may place undo financial burden on families, and often are not covered by insurance or Medicaid. When families do seek help dealing with expensive medical issues from programs like Medicaid or private insurances, they can usually expect to make many phone calls, face delays in services, or deal with denial of services. Parents are often required to justify the child's need for expensive services or therapies to people who have never met the child.

When we first started to look for services, our initial struggle was payment. Who would accept my insurance? At anywhere from $150 to $160 per hour, I certainly couldn't afford the services that Amanda so desperately needed. Basing the selection of a therapist on which insurance they take is not a good way to make the decision.

Dawn

I have made a conscious decision to survive on my son's Social Security Income and child support. I was on Aid to Families with Dependent Children for nine months and hated the degradation and humiliation of state assistance. Now I shop at Goodwill and live within my financial means.

Tonya

Amanda's therapies cost over $2,000.00 per week! Expensive? Yes. A lot for one little girl? Yes. Is it helping? Yes. She is developing by leaps and bounds. It is sad and scary that her future and the degree to which she can be a productive member of society is so directly related to how much money is available for her.

Dawn

I know once Amanda starts school, there will be a struggle to continue to have her see the speech and language therapist who knows her and who works well with her. Instead, the school will prefer that she see the therapist on staff. It would cost more for the school to send her to her current speech language therapist. Why should Amanda lose because of this?

Dawn

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Transportation

Currently, to meet Amanda's needs, she travels a lot. She has 13 therapy sessions per week and attends preschool 40 minutes away, four mornings a week.

Dawn

I now transport Brandon after the local transportation company drove off while he was still standing in the middle of the road, did not properly seat belt him in the vehicle, and "lost" him for a half hour. During that time, I frantically called the preschool, the child care center, his grandmother, and the transportation company to see if they had located my child. I began transporting him with his two younger siblings in tow, five days a week, sometimes two to three appointments a day.

Tonya

I have been to 14 specialists since Matt was born. None have ever agreed on a diagnosis or prognosis. I research, read, and chart symptoms. Not a week goes by that I don't travel one hour each way for a 15 minute appointment with medical personnel who can help develop a treatment plan that fits our day-to-day life.

Sue

Bryce rides the regular school bus to school unless he needs his wheelchair. Kids have been teasing him on the bus about his disability.

Candice

It has been hard to find and keep good drivers who we can trust.

Dawn

The availability of transportation, both public and private, is taken for granted by most people. Under the Americans with Disabilities Act, public buses purchased after 1990 must be accessible to individuals with disabilities. Public rail systems must have one accessible car per train. Unless families live in or near major cities accessible transportation is not typically an option. Because many children with disabilities need access to specialized therapies and physicians who are located at great distances from their homes, parents must transport them. Parents must allocate extra time and/or money for transportation. Even when public transportation is available and accessible, safety is a concern. Most drivers have not received training regarding specific issues related to the disabilities of the children they are transporting, and often cannot sufficiently supervise children to keep them safe. Some parents are eligible to receive reimbursement for their transportation expenses, but the fee is minimal and the paperwork is prohibitive.

I have to call ahead, get pre-approval, fill out forms, and collect up to six pages of paperwork to get 11 cents a mile reimbursement when I take the children to medical appointments. This is ridiculous. Often, it's just not worth it.

Sue

We drive to Bangor, Portland, and Boston for medical appointments. We also drive almost 100 miles on the weekends to wheelchair basketball practices and games.

Candice

The bus is too overwhelming a place for Matt to start his day. He used to do okay because he had the same bus driver and the same seat, the first one on the left near the door. This past year there have been five different bus drivers who cannot seem to allow him to have the seat he needs to start his day. I drive him, his sisters, and his best friend to school every day. It helps us all start our day in a more positive way.

Sue

When Bryce was in the first grade, the driver of the accessible bus refused to take him to his grandmother's house after school if I was working. She told Bryce and me one morning as he was getting on the bus, "I'm dropping you off at home whether any one is home or not."

Candice

The Future

Life with Annie is full of hopes and dreams. I believe Annie can live independently and make outstanding contributions to society. I believe she can be happy and develop satisfying personal relationships.

Roberta

What is important to me is how Amanda's life will be. We need to ask how we can make her life better, help her be more productive, and ensure that she is a fully included member of her community. We need to look at these issues from her perspective.

Dawn

If we start early, we save later. By teaching my son when he is young the things that he needs to know to become part of the community, society will not have to provide extensive support when he is older.

Stacie

I dream of one day having someone in my life who understands the trials and tribulations of a child with special needs. Envisioning being alone for the next 20 to 40 years is too depressing.

Tonya

Brett wants to be a fighter pilot or design Lego kits. He wants to go to his dad's alma mater, Maine Maritime Academy. I know he can achieve these dreams. Will others be willing to help him along the way?

Nancy

I am very optimistic that Brandon will reach his own personal potential.

Tonya

We all look to the future with great hope. For those of us who have children, we dream of a future where they are happy, loved, and successful. The vision of the future for parents of children with disabilities is filled with thoughts of their children being part of a loving, supportive community where they are judged not on their disability, but simply on their ability. They dream of their children graduating with their non-disabled peers, having jobs, being married, having friends they can count on, and living in their own home or apartment. Only when we, as a community, embrace everyone and as a nation provide them with the needed supports, can these dreams become a reality for families who have children with disabilities. As a society, we must recognize the value of each person regardless of his or her level of ability. For every dream there is a corresponding nightmare. Everyone, individually and collectively, has the power to help individuals with disabilities and their families to fulfill their dreams and to avoid potential nightmares.

We all know the pain of not fitting in. We all hope that by some miracle our children with and without disabilities will never face that pain.

Dawn

My dreams for Matt's future are for him to be doing the things he loves, to have friends, and to contribute to society in meaningful ways. I'd love a cure for mental illness when I think the sky is the limit.

Sue

Isn't what we all want for our children, the very, very best? I know I do. Who knows, Nina may be the very first female president.

Diana

I often visualize Bryce at his high school graduation. He has started talking about going to college. I have finally graduated with a degree in special education. I am looking for a teaching job. Maybe we can have a somewhat normal life after all.

Candice

My dream is that Amanda will be respected and valued for her unique and individual gifts and talents, not viewed through her disability.

Dawn

Our dream is that both our children are included in society, and neither is excluded or separated. Everyone belongs to one another as a whole.

Stacie

Before You Decide

Before you decide, we want you to know:

What you can do:

- Honor the commitment to fair and equitable treatment afforded people with disabilities under key legislation (e.g., ADA, IDEA, Section 504, FERPA)
- Know a parent(s) in your area who can give feedback
- Be respectful and polite
- Provide parents in your area with copies of legislation/policy in language that is understandable
- Call the key parent organizations to obtain information on the potential impact of decisions
- Believe that all families are valuable resources
- Review your office protocol to ensure "family-friendly" interactions
- Help connect parents with agencies, groups, and/or individuals who can offer them support
- Understand the impact that your decisions have on individuals with disabilities

What we can do:

- Explain the effects that proposed legislation/policy can have on individuals with disabilities and their families
- Share real life situations with policy makers who do not have the experience living with an individual with a disability
- Be respectful and polite
- Sit on committees, panels, task forces, or boards of directors
- Testify
- Give you feedback when your efforts are successful
- Care for ourselves and our families
- Advocate for our children
- Be a support to other parents who have children with disabilities
- Have a cup of tea with you and talk

Linda Chamberlain is the aunt of a child with a disability. Chris is her beautiful, eleven year old nephew who has autism. He lives with his mother and younger brother. Chris attends Memorial School in New Gloucester. He has enthusiastically participated in Special Olympics, where he last year was awarded gold, silver, and bronze medals. He enjoys being with family and especially looks forward to spending time with his cousins. Chris also loves to visit his great aunt.

Esther Chesley is mostly at home with a few hours working in a small boarding home for senior ladies. Esther says, "I am married to a wonderful man named Bruce, who can do just about anything. We have a terrific boy, Grant, who is 13 years old. He loves to read and enjoys sports. We are now the legal guardians of Travis, a 10 year old boy with several different problems. He is an enjoyable child who is bright, generous, and full of affection. We have spent the last year adapting to each other as our family has changed."

Stacie Clement has been married for 12 years to a wonderful and courageous man, Charlie. He has always been there when times were difficult. They have two terrific boys, Carl, 12 years old who is in the seventh grade and Adam, who is 8 years old, has autism, and is in the third grade. Adam loves puzzles, listening to music, reading, art, and camping outdoors with his brother and his dad. He loves his family very much and he has a lot of people who care about him. Stacie states, "Having a child with a disability has taught us to be more patient and more sensitive to others. Everyday we plan to move ahead."

Dawn Cummings and her husband, Wayne, have been married for 7 years and live in Norway. They have two beautiful girls, Amanda, 5, and Allison, 3. Amanda is legally blind and has developmental delays. Amanda loves music, videos, playing with her friends, and working on the computer. In addition to being a mother and wife, Dawn works full time as a manager at an insurance company. Dawn is a volunteer advocate for children with special needs with Maine Advocacy Services. Dawn is a board member for the Developmental Disabilities Council.

Chris

Travis

Adam

Amanda

Sue Henri-MacKenzie *lives in East Lebanon, Maine with her three children, Cassandra 10, Matt 9, and Micheala 6; their cat, Punky; and rabbit, Raisin. All three children have special strengths and special needs. Sue has been active in many projects, organizations, and committees concerned with the quality of life for people with disabilities and their families. Sue teaches American Sign Language. She is a member of the York County Case Review, and the Parent Advisory Council on Early Intervention. She has just completed a handbook on transition to kindergarten.*

Martie Kendrick *lives in Bar Mills, Maine with her husband, Brian, and two teenage sons, Asher and Zachary. Asher, who has Asperger's syndrome, is anxiously approaching his senior year in high school and has just purchased his first car. "Our family worries that when Asher leaves schools there will not be the necessary supports available to propel him into a satisfying adult life." Martie is also an Educational Specialist at the Center for Community Inclusion, Maine's University Affiliated Program. Martie co-instructed the Family Leadership Training.*

Tonya Labbe *is a single mother of three children, Spencer, 2; Kirsten, 4; and Brandon, 6. Brandon has been diagnosed with Pervasive Developmental Disorder and Oppositional Defiant Disorder. He looks like any other five year old. His boyish looks and charm tend to win over even his most fierce opponents. Tonya is constantly advocating for Brandon and attends many conferences and seminars in order to further her own knowledge. She firmly believes that Brandon and she are trailblazers and pioneers with the system.*

Janice MacDonald *is married to a great guy named Bill. They have two children. Sarah is 5 years old and is very outgoing and independent. Scott is a very active eight year old who has Bipolar Disorder and Attention Deficit/ Hyperactivity Disorder, which are neuro-biological disorders. Janice worked for 12 years as a nurse in the Recovery Room. When things became too hectic for Scott at school, she stopped working to provide Scott the intensive adult supervision he needs. She belongs to two support groups and an on-line support group. She shares information, articles, and support to other parents.*

Matt

Asher

Brandon

Scott

Diana McNally *has been married for 19 years. She and her husband, David, have four great kids. Erica (18) is a senior at the Maine School of Science and Math. David Jr. (16) is a junior at Gray-New Gloucester High School. Nathan (12) is a sixth grader at Gray-New Gloucester Middle School. Nina (6) is a kindergartner with severe oral and verbal dyspraxia and sensory issues. Diana says, "As far as I'm concerned, all children are special. It does not matter if they are gitted or have special needs. They all have the right to be taught to the best of their abilities."*

Nancy Niles *has been married for 14 years. She and her husband, Dan, have two wonderful, energetic, bright, creative boys with Attention Deficit/Hyperactivity Disorder (ADHD). Like all children, Brett, 12 and Kurt, 9, can both be a source of pleasure and aggravation. Nancy was a teacher for a number of years before going to work at the Maine Parent Federation teaching parents how to access resources to meet the needs of their children. Nancy recently moved out of state and plans to continue her advocacy on behalf of families who have children with ADHD.*

Roberta Raymond's *highest commitment is to her family. Her husband of 17 years, Jeff, is and always has been a strong and loving companion. They have two wonderful, bright, and energetic children. Jake is 13 and Annie is 7, with cerebral palsy. Roberta feels that "If we allow our children to be who they are and give them our love and respect, they will grow strong and free to reach for their own dreams." Roberta has been a special education and classroom teacher, is a graduate of Boston University, and has her Master's degree in Special Education from the University of Maine at Orono.*

Candice Russell *lives in Plymouth, Maine with her two children Bryce, 11, and Emma, 7. Bryce had Neuroblastoma when he was an infant. A spinal tumor caused paralysis so he wears leg braces. He is bright and extremely energetic. He is interested in sports and plays on the "High Rollers," the first wheelchair basketball team in Maine. Emma loves animals and is very artistic. Candice enjoys music and dogsledding. She has a Bachelor's degree in Art Education and a Master's degree in Special Education. She is currently tutoring children with chronic illness or disabilities in their homes or hospital.*

Nina

Brett

Annie

Bryce

Before you decide, let me tell you about my family: